

State Council on Developmental Disabilities/Area Board 6

Annual LQA Trends, Issues, and Needs Report FY 2003-04

October 29, 2004

**State Council on Developmental Disabilities/
Area VI Developmental Disabilities Board
2529 March Lane Suite 105
Stockton, CA 95207
Phone : (209)-473-6950 Fax: (209) 473-6952
E-Mail: info@areaboard6.org**



LQA Summary Data: Trends, Issues and Needs

FY 2003/04

Introduction

Since 1997, the Area VI Board has conducted Life Quality Assessments (LQA's) for individuals who use regional center services in the area of Amador, Calaveras, San Joaquin, Stanislaus, and Tuolumne counties. The assessments, or LQA's, are intended to capture the individual's perspective on the quality of his or her life, in order to enrich the individual's planning process (IPP). Summaries are routinely conducted for persons who live in situations other than with their family of origin. However, any regional center client can request and receive an LQA visit.

In addition to the individual planning process, the LQA summaries provide an overall view of the issues, concerns, and needs experienced by eligible adults and children with developmental disabilities. As part of the State Council on Developmental Disabilities' mandate to identify issues and needs for persons with developmental disabilities, the LQA Summary data results have also been reviewed in aggregate.

Just as the individual summaries are intended to contribute to, but not supplant, an overall planning process, so this report is intended to be one tool in the information gathering and assessment process that underlies effective resource development. LQA data is highly subjective, reflecting as much as possible the individual's self perceptions at the time of the visit. The more successful the visitor is in catching that perception, the more useful the LQA is in informing the individual's planning team of personal needs and concerns. Trends in aggregate data represent common experiences, and as such, provide vital insights into the service system and generic support systems in our communities.

Project Design

The format, methods, and standards for conducting LQA visits were developed by the Department of Developmental Services (DDS), and are standardized throughout the State of California. This project relies primarily on trained volunteers, who receive a stipend for completing summaries. They are expected to generate over 12,000 volunteer hours over the duration of this three year project cycle. The project is staffed by two Community Program Specialist positions and a half-time Office Assistant.

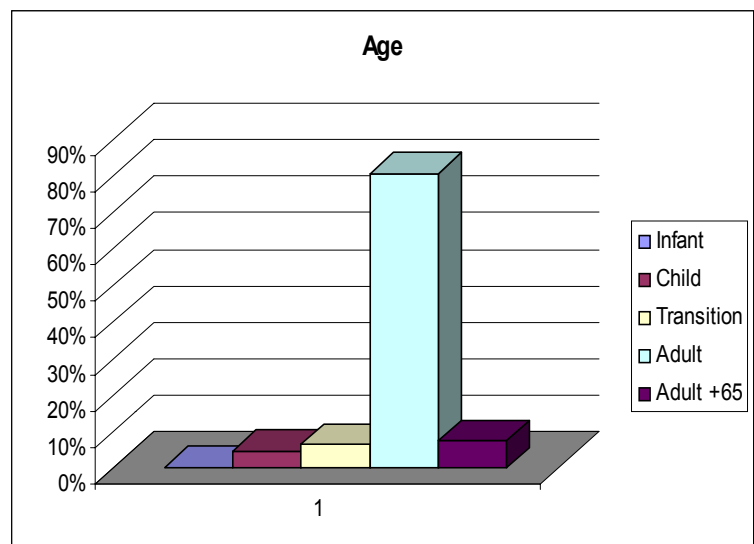
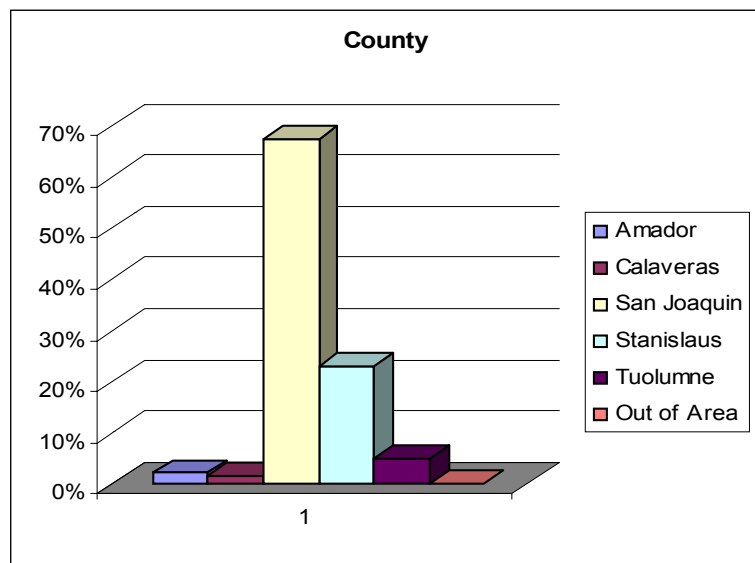
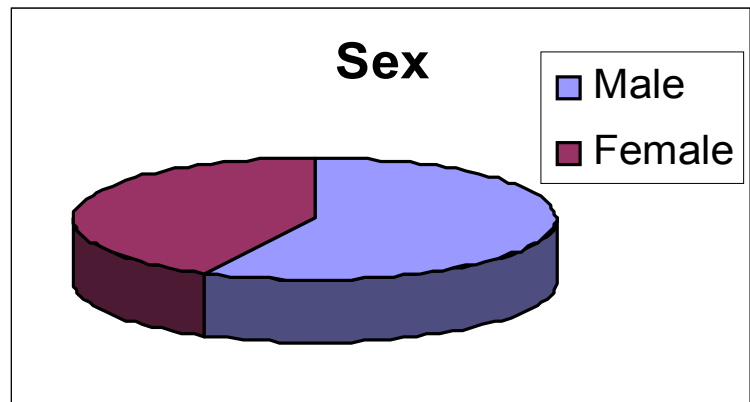
LQA Summary Results

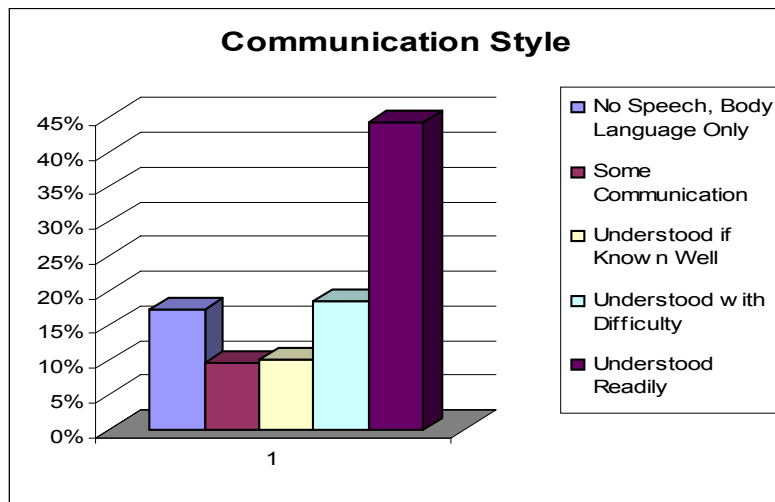
The LQA process looks at 25 life outcomes, grouped into six areas. For each outcome, the visitor indicates either "OK at this time" or "Needs Follow-up", and then documents the observations and comments that explain their conclusions. "Needs Follow-up" is indicated for several reasons. The visitor may not have been able to observe any information about that particular outcome, so the status is unknown. "Needs Follow-up" can also reflect known issues that are being addressed but not fully resolved, or issues that most probably can't be changed but rather reconciled, such as physical losses related to aging. Response to "Needs Follow-up" issues is the responsibility of the regional center and individual planning teams.

Overview

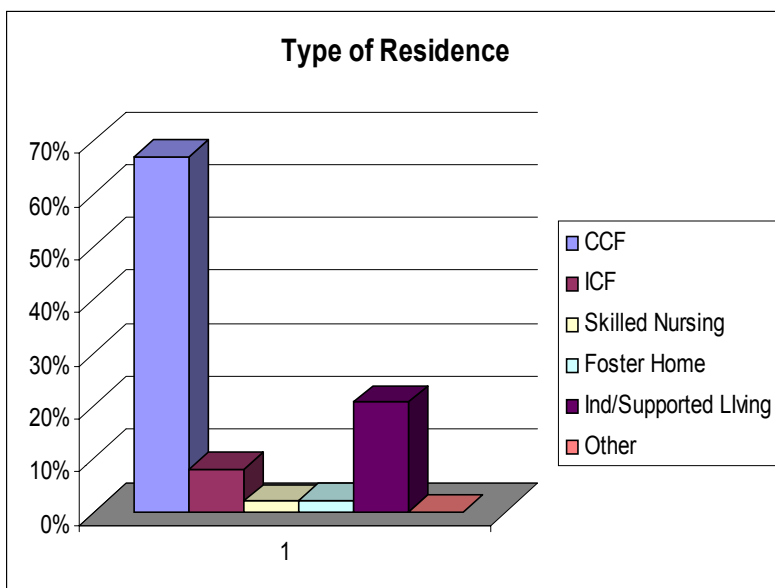
Visitors and LQA staff completed 593 visits, and attempted to complete an additional 242 visits. These attempted visits were not completed for a variety of reasons, such as a major illness or incarceration. People also declined to have visits. Some people declined because they felt their lives were going very well. Others declined for a variety of personal reasons, such as work or family demands. Valley Mountain Regional Center (VMRC) Service Coordinators were helpful in efforts to make contact. By far the majority of service providers were also very supportive of each person's right to have a Life Quality visit.

As in previous years, visitors found that most of the people they visited are in safe situations and that their basic needs are supported successfully. The living arrangements and supported day time activities varied through a wide range of service options. Visits were conducted in all five counties of the VMRC catchment area, and both adults and children living in situations other than with their family of origin were visited. People who were visited during the third year of the previous project cycle were contacted again for repeat visits this year. Visitors again found that many issues raised in the previous visit had been addressed, particularly those who had had potential rights violations. The overall pattern of services for most people had not changed significantly.

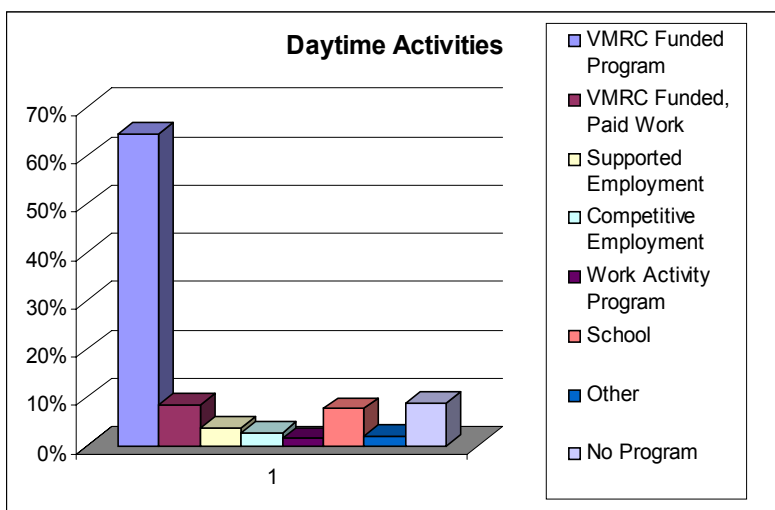




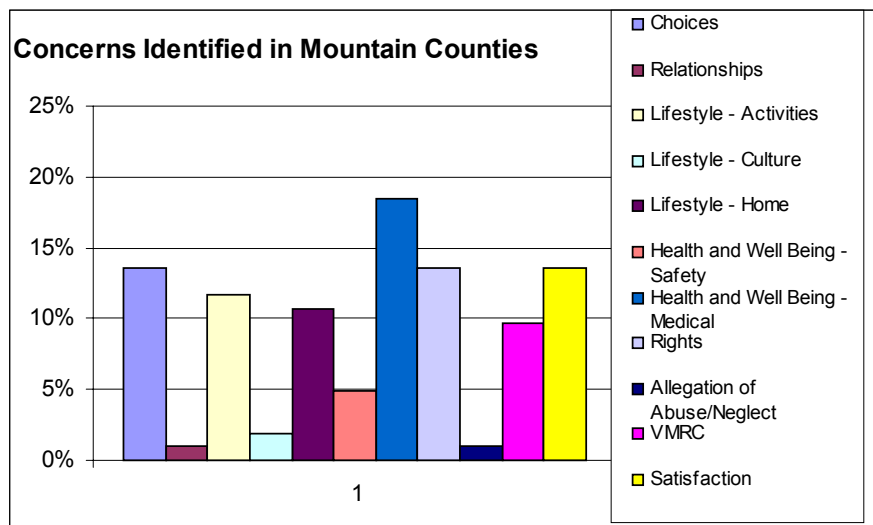
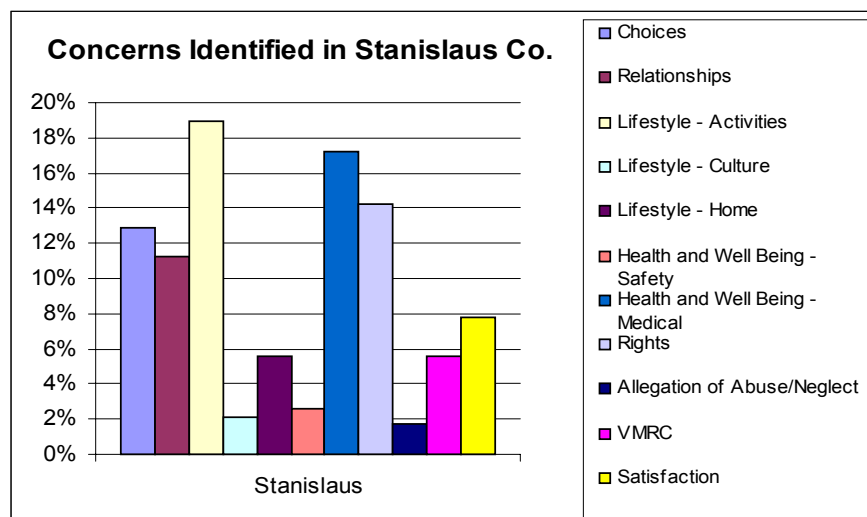
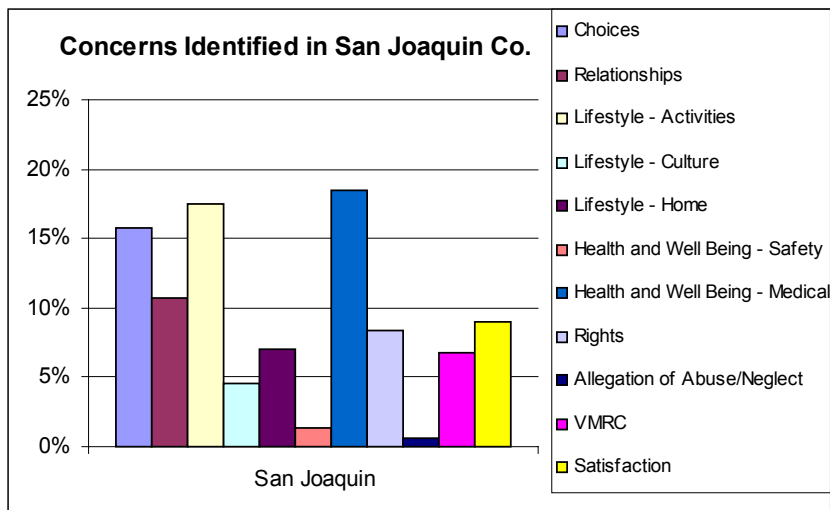
The majority of people visited lived in a community care facility, ranging from 6 beds up to 49 beds in size. They attended a regional center funded program. That majority represents not only the most common circumstance for VMRC clients, but are also the people most likely to agree to a visit. People living independently were mostly likely to refuse a visit.



With the exception of a small attendance at other publicly funded programs such as community colleges, adult day treatment or substance abuse rehabilitation programs, adult daytime activities were primarily funded by the regional center. The only work activity program in the five counties is in Stanislaus. Only 23 people visited in the five counties used supported employment services.



The same patterns of concerns emerged again this year, suggesting underlying common causes. Many concerns, such as problems with safe and decent rental housing are common to poverty. Some concerns are certainly common in the shared human experience, such as longings for closer family ties and friendships. As in previous years, people in the mountain counties tended to express a greater sense of autonomy and satisfaction overall. However, the mountain counties were also characterized by a natural screening effect, as people who have more problematic support needs tended to congregate in urban communities.



Emerging Trends

Forty-two percent of the people visited identified no follow-up needs, almost identical to the previous year (41%). Again, the majority of those who identified follow-up needs had less than three issues. Many issues were life enrichment concerns, such as learning new life skills. While areas for system improvement continue to emerge, the foremost observation is that the majority of people visited are greatly or mostly satisfied with services they receive.

Residential Services

Twenty-five individuals visited expressed a desire to move from their current carehome. Many wanted to move to different areas or to move to a less restrictive setting. An additional 19 people complained about significant conflicts with housemates. Three of the individuals wanting to move were restricted in their choices because of legal constraints. Other complaints included concerns about food, activities, and restrictions of communal living. In all, 8% of the people living in licensed facilities were dissatisfied with their living situation. The desire for a place of one's own remains a dream for many of these individuals, as the overall number of people using supported living services remains relatively static throughout the five counties. It should be noted that the LQA visitors do not assess barriers to supported living arrangements, but merely noted that the individual's expressed preference for those services had not been realized.

Unlike the two previous years of this three year project cycle, visitors only noted one instance of cutbacks in weekend activities.

Cutbacks were also cited by individuals receiving supported living services, or doing without supported living services. Specifically, these complaints related to overall reduction of hours, and unavailability of support during the medical appointments. People who were not receiving services and who expressed a need for services had typically encountered a new problem in their lives, such as a rent increase, and needed assistance before their problems became a crisis.

Visitors also found several people in marginal living situations. Three people were living in motels, one person in an improperly converted garage, and four people were facing eviction or in temporary housing. These numbers are small, but are all related to the escalating costs of housing in this catchment area. Unique barriers were also encountered. One married couple were sharing a room with a female, nonrelational, roommate, waiting for a private room to become available to them. One married couple was living apart because of age restrictions on the respective facilities. Two people were facing relocation because of their ages.

Residential Services for Children

Two children were living in transitional crisis housing on a long-term basis and one adolescent was living with only adult housemates, due to the unavailability of homes for children in need of behavioral intervention services.

Day Activity Services

Forty-six people visited wanted changes in day programs, exactly twice the number as the

previous year. Again, complaints about day programs were almost all related to the day program being “boring” or not providing enough to do. Of the 54 individuals visited who were not receiving day time services, 5 specifically mentioned that they had rejected day program services as programs as boring, stigmatizing, or unable to meet their activity preferences. Dissatisfaction was slightly higher in Stanislaus county, and lowest in the three mountain counties.

Fifty people expressed a desire for employment or better employment. Twelve people wanted a better job, or more hours on their current jobs. In total, 20% of the people visited expressed dissatisfaction with daytime activities. After three years of the same trend, there is a strong indication of significant problem in the day time services currently being offered to people who use regional center services. Because these complaints are area wide, this trend suggests systemic issues.

There was also indication of systemic response to these concerns. Twelve percent of the people visited who used day program services also had jobs as part of their day program services. Some day programs were also offering flexible hours, including evening activities, to better meet individual preference and social needs.

Medical

Health concerns emerge annually, and are most probably endemic to the population visited. Service coordinators were almost always aware of those concerns. Difficulties were most often systemic or attitudinal barriers, and similar to previous year results. Needs included adaptive equipment or equipment repairs, follow-up with specialist, wellness activities to maximize health such as smoking cessation and weight loss. Sleeping disorders emerged again as a health problem. Access to services not covered by Medi-Cal, including medications, or not provided with sufficient frequency, such as glasses, was also a concern. The practice of individuals having to change their doctors when they move to a new care home was observed again this year. Individuals did not view choice of health providers as something they could do. Dental needs were identified by 39 individuals, and continue to be the most frequently cited medical need.

Three individuals or their foster parents expressed frustration in getting assessments for needs related to the possibility of neurological problems or autism. These foster parents did not have an established relationship with regional center service coordinators, and did not see the regional center as a significant resource to their family member.

Families with Dependent Children

Visitors met 16 individuals who had children under the age of 18. Again, visitors are finding an increasing success in supporting families when one or both parents use regional center services. An additional 6 parents were visited who had children in some sort of placement arrangement, often with other family members. When those children were living with them, these families typically received supported living assistance and were satisfied with those services. Four parents requested additional parenting support services, including skills

training and day care. Three individuals had legal concerns regarding custody. Five individuals wanted employment that would accommodate their family needs. Four families were living in substandard housing in unsafe neighborhoods. Other needs included social and recreational resources, generic resources including childcare, and counseling. One family were non-English speakers, and encountered service and community barriers as a result. For those families who had children in placement, two requested legal assistance regarding custody. Another mother wanted a picture of her child. Three people visited had adult children living with them, and another 6 individuals had adult children living independently. One of those families wanted help locating the adult child. One family needed help with custody of grandchildren.

Spiritual Needs

Twenty-two people identified unmet spiritual needs. Barriers included transportation, distance from preferred church, and no staff support to attend preferred services. One person complained that they had to attend to the church of their provider's choice. Like other cultural sensitivities, there is varying valuing of spiritual activities among providers, and varying accessibility within faith organizations. Visitors also noted some homes where individualized support was provided effectively so that consumers could participate in their preferred faith communities. It was not clear to visitors why some homes provided that individualized support while others did not.

Summary Results by Category

Choice

The "Choice" category includes information about the ways that individuals identify their needs, wants, likes and dislikes; how they make major life decisions; how they make everyday decisions; the role they have in selecting providers of services and supports; and how their services and supports change as wants, needs and preferences change.

The majority of individuals visited were still satisfied with their choices. As discussed previously, the trend of dissatisfaction with the choices offered in care homes and day programs has continued. Communication continues to be a barrier to making choices. Support staff often relied on ability to interpret the individual's personal communication based on long-term relationships, without assistive tools, and often did not express concern about the dependency that engenders. Seven individuals had restricted access to assistive communication devices, because they were unavailable in some environments or direct care staff was not trained in their use.

Most people living in their own homes expressed satisfaction with the choices that they made in their lives. Problems with limited choices were typically related to food and activity options. Other concerns related to room decorations, roommate selection, and service providers. Five people, who were otherwise unrestricted in their right to make decisions for themselves, stated that they didn't agree with decisions that are made for them by family, staff, and in three instances, by their Service Coordinators. One individual did not have a current IPP, and two individuals did not have a known transition plan.

Relationships

The Relationships category includes information about individuals' friends and caring relationships; and whether they have community supports that can include their family, friends, service providers, other professionals, and other community members. Relationships are always central to the quality of an individual's life, and are frequently areas of concern.

A slight increase over last year, 14% of the people visited identified relationship concerns. Twenty people complained about problems with roommates. While most of these complaints related to personality conflicts, some complaints included fear of assault and frequent sleep disturbance. One person expressed fears about a classmate at day program. The desire to find or spend more time with family continued to be the most commonly expressed issue. Twenty people wanted to visit out-of-area family. Three people wanted phone numbers to call a family member, and two people wanted help locating siblings. Alternatives like e-mail, video or picture exchanges were not often mentioned as strategies to connect families. Ten individuals expressed loneliness and a desire for friendships. Three people wanted to visit their former homes and reconnect with support staff they had known in the past. One person wanted to start an epilepsy support group. Behavioral concerns were cited for four people, as significantly interfering with social relationships.

When housemate discord involved violence, the violence was still viewed as a behavioral issue rather than an abuse issue. Again, visitors observed that there did not appear to be much concern regarding emotional well being and traumatic stress when assaults involved housemates who both used services, or between individuals using the same day program services.

Lifestyle

Lifestyle is a broad category, including if the individual is part of the mainstream of the community; if their lifestyle reflects cultural preferences; if they are independent and productive; if they have stable living arrangements; if they are comfortable where they live, and if children who are regional center clients live at home with their families. In part because of the range of the lifestyle category, the greatest number of concerns was identified under this category. Consequently, in the summation bar graphs, lifestyle concerns are broken down into three subcategories. As in previous years, issues ranged from small changes to lifestyle reordering.

Dissatisfaction with day services has increased from 9% of people visited in the first year of this project cycle, to 20% last year, and 20% again this year. This year, complaints were split evenly between dissatisfaction with available day programs and the desire to be employed instead of having traditional day program services. Nine percent of the people visited were employed through day programs. Eight percent were competitively employed or using supported employment services.

Other issues included more time in the community and more activity overall. Twenty people wanted to spend more time in the community; four people specified weekend and evening activities. Fourteen people wanted to take classes at community college or vocational school. Thirty-four people wanted specific skills training, such a learning to cook or read.

Two people mentioned learning to use the internet. Four people had transportation barriers that prevented them from being involved in their communities. One of those people was at risk of losing their job. Two people wanted to learn to use public transportation. Six people needed bus passes.

Cultural needs were identified in visits with 30 individuals. A familiar pattern, visitors observed that providers were generally making efforts to build cultural elements into the services they offered through menu offerings, activities, and home decor. American Anglo continues to be the dominant culture. No community care facility visited used Spanish as the common language within the home. Cultural needs were also expressed for individuals of the Moslem and Mormon faiths and Native American ethnicity.

With the exception of 14 individuals visited, people were settled in stable housing. The majority of people visited were in clean, safe, and reasonably comfortable settings. Eight per cent of the people in licensed facilities were unhappy with their homes, and 4% specifically requested a change in their home. As in previous years, most complaints related to limits in choices, conflicts with housemates and providers, and the desire to live in other communities. Twenty-one percent of the people visited this year were either living independently or receiving supported living services. Of this group, 20% had dissatisfactions with their living circumstances, usually related to poverty issues such as the small size of their housing units or substandard housing.

A significant gap in services was identified for 3 children who have serious behavioral intervention needs. Two children were living in placements designed to be short term, crisis situations, and one adolescent was living in a home with only adults as housemates. In all three instances, the service coordinators were aware of the difficulty but simply did not have any alternative resources available locally.

Health and Well-being

Issues and the number of people expressing concerns have been similar in aggregate data annually. Individuals living independently or with supported living services almost always knew about 911 and how to get assistance in an emergency. However, four of those people had no working smoke detectors or fire extinguishers. Six people did not feel safe in their neighborhoods. Staff were able to specify how they would recognize that an individual who does not use words was ill or hurt. Three people were fearful of assault from other people who use services. One person had been injured by a broken wheelchair, recent to the visit.

Twenty-seven percent of the individuals visited identified one or multiple wellness or health concerns. Eight people asked for help in improving their health through exercise, diet, and smoking cessation. Thirteen people had problems with repair or replacement of durable medical equipment, most frequently wheelchairs. Four people were in need of specialists, including neurologists. Four women had OB/GYN needs. Eleven people reported problems with medications, including nausea, vomiting, excessive sleepiness, and dizziness. Four people were dealing with post-surgical health issues.

Three people had health problems exacerbated by situational problems, such as housemate smoking or noise. Six people described chronic sleep disturbance over a prolonged time

period. Other problems included illness or treated injuries recent to the visit. Other chronic health problems, such as stomach pain, feeling tired, and halitosis, were identified for 11 individuals. Two people were in need on toenail care.

Rights

The Rights area of the LQA gathered information on the individual's exercise of personal rights as a person who uses services and as a citizen; whether or not the individual is free from abuse, neglect and exploitation; if the individual is treated with dignity and respect; if the individual is receiving appropriate generic services and supports; and if the individual has advocates or access to advocacy services.

The understanding that individuals had regarding personal rights varied widely, and was not necessarily related to the degree of supports being provided to that individual. Visitors often used a copy of the client's rights poster distributed by the Department of Developmental Services to talk about rights. While concept of rights was an abstraction for many people, people were typically able to understand the specific examples used by DDS to illustrate rights. As in previous years, most visitors observed respectful and even affection interactions between individuals and the people who support them.

Twenty-seven percent of the individuals visited identified concerns in exercising their rights and responsibilities again this year. Fifteen of those people wanted to learn to speak up for themselves and to exercise their rights more effectively. Two individuals specifically requested involvement in People First or self advocacy groups. Four people wanted rights and IPP training, and 2 parents wanted special education rights training. Greater control in life was a frequently expressed desire, especially control over finances. Twelve people wanted to change payees, and eleven of those people wanted to receive their money directly. Other ways that people wanted more control related to personal choices, such as with clothes, without control by family or service providers.

Seven individuals alleged violations of their rights that were potentially abusive or exploitive. Two of these complaints involved support staff. The remainder of the complaints related to conflicts with housemates, people at day programs, or personal relationships. One person was involved in a legal case of alleged misconduct by a public guardian. Ways that people felt their service rights might have been disrespected included things such as belongings being set on a shelf too high to reach, household curfews, phone use restrictions, and smoking restrictions. One person felt that their needs were neglected by care home staff. An additional 21 individuals complained of feeling disrespected by paid staff (4), peers, family, neighbors, and members of the community such as bus drivers. Privacy, particularly having a private phone was raised as a problem by five people. One person complained about care home staff speaking to each other in a language other than English. One day program staff person complained about the treatment by care home staff towards the individual visited. Four people had rides between their homes and their day programs that were longer than two hours, and one person had a long walk to a bus stop, because the program bus would not drive up the access road to the home.

Most people visited were using generic services and supports successfully, most typically

public transportation, financial aid, and housing assistance. Forty-six individuals identified problems with generic services, many of which needed advocacy assistance. Problems included straightening out SSI payment difficulties, denial of services by Dial-a-Ride, applying for Section 8 housing assistance, getting personal identification and records, and immigration status. Custody was an issue for 4 families, and one family needed help with an adoption process. One person had problems with access in a gated community.

Legal services were needed by four people dealing with landlord/tenant issues. Two people needed legal assistance with estate issues, two with medical rights, and two people had personal injury legal concerns. One person requested assistance with criminal legal proceedings.

Thirty-seven people identified issues related to Service Coordinators and VMRC services, the same number as last year. Some of the issues raised were matters of personal preferences, for example wanting a specific Service Coordinator. Five people had not met their Service Coordinators at the time of their LQA visits. Two people did not have transition plans.

Four people disagreed with decisions that their Service Coordinators made. The majority of complaints fell into three areas – frequent turnover of Service Coordinators, slow response, and unsatisfactory accounting information regarding personal funds. Two people complained that their Service Coordinators were not assisting them in getting personal belongings from a previous home. Three people complained about personal information in regional center records.

Satisfaction

The Satisfaction area of the LQA addresses whether or not individuals achieve personal goals; if individuals are satisfied with services and supports; and if individuals are satisfied with their lives.

Satisfaction is difficult to assess, particularly for people who do not use words to communicate. But for the most, people appeared to be content with their lives. People generally lived in attractive and comfortable settings, and felt that they were supported with care and respect. Almost half, 42%, of the people visited identified no follow-up needs at all. Many of the issues that were raised, such as wanting more contact from family, were most probably not resolvable through regional center services.

Hearing about people's dreams is an especially enjoyable part of LQA visits. This year, 54 people shared future hopes. Lots of dreams included traveling. People wanted to get married, buy their own homes, drive their own cars, and achieve career goals. Some dreams were well within reach of the planning team, such as a visit to Disneyland or going camping. Others, like having a book published, might be lifetime dreams. Visitors were able to help some people with similar dreams of writing their stories to connect with a peer who has realized that dream.

As already discussed, people talked about wanting different kinds of services, new day programs, different workers, and people who could help them achieve their ambitions. In addition to those issues already discussed in this report, 24 people expressed dissatisfaction

with one or more support staff or service agencies. Most frequently, those complaints related to the reliability and quality of supported living services, IHSS services, and to the absence of any desired services.

Conclusion

As in previous years, the overwhelming conclusion of the data is that people are, for the most part, being supported in ways that meet their needs respectfully and effectively. The impact of low income is greatly ameliorated by support networks.

A significant finding in this year's data relates to the availability and quality of residential services for children. Service coordinators reported that long-term placements for three children with behavioral difficulties were simply not available in the VMRC catchment area at the time of the visits, and had not been available for some time.

Visitors observed efforts to respond to the increasing dissatisfaction in day service options through increased employment and variable schedules. In Tuolumne county, 57% of the adults visited were employed at some level through their day programs, and one student was receiving vocational training in a transition program. Although only 30 people were visited in that rural county through the year, the rate of employment is still noteworthy. Other areas did not have equivalent employment patterns. Overall, 20% expressed dissatisfaction with day services again this year, a trend that merits serious consideration.